

**Brief Report**

## Feasibility of Weekly Integrated Palliative Care Outcome Scale (IPOS) Within a Stepped Care Model

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**Abstract**

**Context.** Patients with advanced cancer may experience symptoms and concerns that are inadequately identified by the healthcare team, leading to calls for patient-reported symptom monitoring.

**Objectives.** Assess the feasibility of administering weekly patient-reported online Integrated Palliative care Outcome Scale (IPOS) questionnaires within the context of a stepped care model in the outpatient care setting.

**Methods.** Analysis of intervention group data in a randomized controlled trial to assess the effectiveness of a stepped care model of palliative care for patients with advanced cancer. Patients in the intervention group were invited to complete the IPOS weekly for 16 weeks through a remotely-administered online questionnaire. At the end of the 16-week period, patients were invited to complete a feedback survey. Multivariable logistic regression was used to assess factors associated with more versus less than 70% completion of weekly questionnaires.

**Results.** Among 111 patients who survived more than 16 weeks, the mean number of questionnaires completed was 9.2/16 (58%). A total of 53 out of the 111 patients (48%) completed more than 70% of the questionnaires. Higher education level was found to be associated with higher completion of the questionnaires. A total of 79 out of 111 (71%) patients responded to the feedback survey, of which 67 (85%) felt comfortable with completing the online questionnaire and 11 (14%) felt it was troublesome to complete it on a weekly basis.

**Conclusion.** In our study, there was suboptimal completion of patient-reported IPOS questionnaire. Further research is needed to improve the uptake of patient-reported outcomes in real-world clinical settings. *J Pain Symptom Manage* 2024;000:e1–e9. © 2024 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights are reserved, including those for text and data mining, AI training, and similar technologies.

**Key Words**

*Palliative Care, cancer, patient reported outcome measures, symptom screening, feasibility studies, telemedicine*

**Key Message**

Patients with advanced cancer may experience concerns that are inadequately identified by the healthcare team. Patient-reported symptom monitoring could be used to proactively identify and manage these concerns. However, we found suboptimal completion of weekly IPOS questionnaires; research is needed to improve uptake of patient-reported outcomes in real-world clinical settings.

**Introduction**

Patients with advanced cancer may experience various symptoms and concerns arising from either cancer treatment toxicity or the cancer itself. However, many of these concerns are inadequately identified, assessed and addressed by the healthcare team, leading to calls for patient-reported symptom monitoring.<sup>1,2</sup> For cancer patients receiving chemotherapy, remote symptom monitoring was found to be feasible with high patient-

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reported outcomes completion rate, albeit in a clinical trials context, of about 89% at six months.<sup>3</sup> Symptom monitoring with patient-reported outcomes during routine cancer treatment was found to lessen symptom burden and improve quality of life.<sup>4–8</sup> However, this model of routine symptom monitoring and prompt treatment of identified symptoms and concerns has not been extensively tested in the broader context of identifying palliative care issues among patients with advanced cancer who may not be on active chemotherapy.

Palliative care symptoms and concerns that patients with advanced cancer may experience range widely from physical symptoms such as fatigue or poor appetite, to psychosocial issues such as feeling depressed or anxious, or having unmet information needs. The Integrated Palliative care Outcome Scale (IPOS) is a brief global measure of such symptoms and concerns that was developed initially in the UK.<sup>9</sup> It has since been translated to several languages and validated in several geo-cultural contexts.<sup>10–13</sup> In Singapore, the IPOS was translated to Chinese and both the English and translated Chinese versions were validated in the Singapore context.<sup>13</sup> The IPOS could potentially be used to monitor for emergent palliative care needs, so as to identify and promptly address these needs. Symptom screening with IPOS could be deployed within a stepped care model – where patients who are more affected by symptoms and concerns receive higher intensity of palliative care.<sup>14,15</sup>

Our main objective was to assess the feasibility of administering weekly patient-reported online IPOS questionnaires within the context of a stepped care

model in the outpatient care setting. In the stepped care model, completion of questionnaires is important as questionnaire responses are used to determine the level of palliative care that the patient would receive. Therefore, we aimed to determine the prevalence of palliative care concerns identified by the IPOS, the IPOS questionnaire completion rate, factors associated with a higher completion rate, and acceptability of the weekly online questionnaires to patients.

## Methods

### Study Design

This study analysed data from the intervention group in a randomized controlled trial primarily designed to assess the feasibility and effectiveness of a stepped care model of palliative care (SPARKLE - Supportive and Palliative care Review Kit in Locations Everywhere) to improve patient outcomes of quality of life and acute healthcare utilisation. Findings from the trial will be published elsewhere. Enrolled patients with advanced cancer were randomized to either usual care or the intervention group. In addition to usual care, patients in the intervention group received a stepped care approach with weekly symptom-monitoring. Patients were invited to complete the IPOS weekly for 16 weeks through a remotely-administered online questionnaire. Depending on how participants completed the IPOS items, the SPARKLE nurse would take certain actions according to the workflow shown in Fig. 1. According to the workflow, if any symptoms and concerns were identified by the online IPOS survey, the

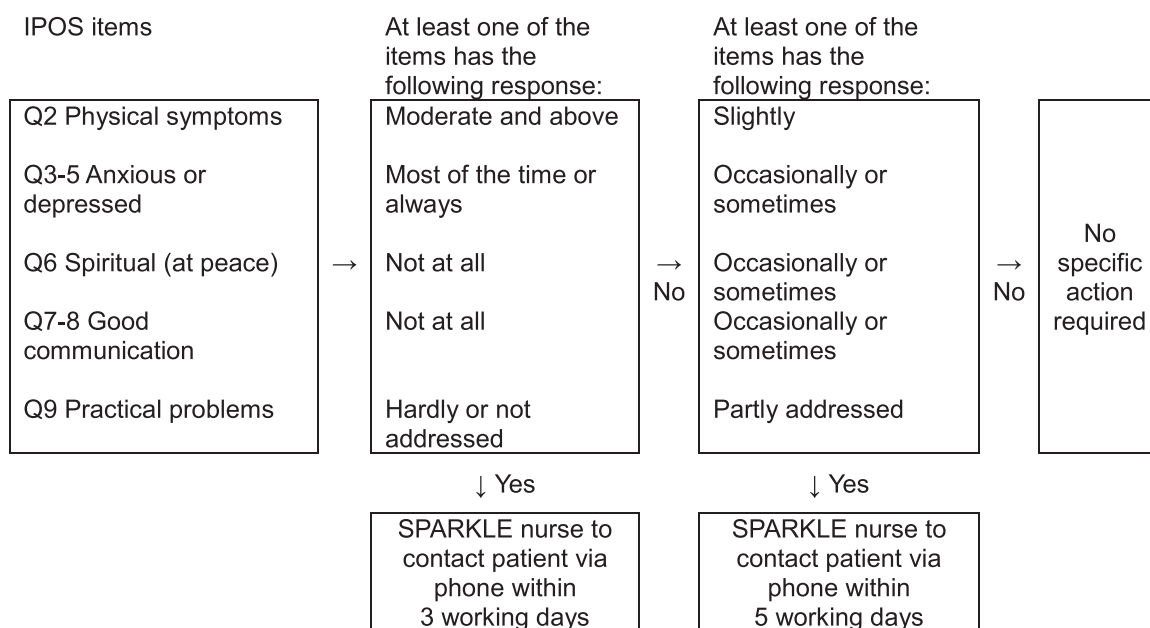


Fig. 1. Workflow for patient responses to integrated palliative care outcome scale (IPOS).

SPARKLE nurse would make a phone call to the patient within three to five working days to conduct a triage assessment of the identified symptoms and concerns. If the symptoms and concerns are assessed to be complex or severe, the patient would then step up to a high-intensity level of care which is an in-person review by a specialist palliative care clinician (ClinicalTrials.gov ID NCT04242251).

### *Setting and Participants*

The study was conducted in the National Cancer Centre of Singapore (NCCS), which has over 140,000 outpatient attendances a year, covering 65% of all cancer patients in the public sector in Singapore. Eligibility criteria for the study were: (1) adult aged 21 and above; (2) diagnosis of stage four solid tumour, without restriction on time of diagnosis. Exclusion criteria were: (1) unable to complete patient-reported outcome measures; (2) already under the care of a specialist palliative care service.

### *Data Collection*

Demographic and clinical data were extracted from the electronic medical records. For those in the intervention group, enrolled patients received a weekly invitation via SMS link over a 16-week period to complete a self-reported online symptom monitoring questionnaire using IPOS. No reminders were sent if patients did not complete the online questionnaire. Patients chose whether they wanted to complete the IPOS questionnaire in English or Chinese. The IPOS is a 17-item questionnaire that assesses for how a person is affected by symptoms and concerns experienced by advanced cancer patients in three domains of physical (10 items), emotional (four items), and communication and practical issues (three items). Each item is rated on a Likert scale of zero to four. Higher scores indicate that symptoms and concerns affect the person more.

At the end of the 16-week period, patients were invited to complete a five-item feedback survey which included two items specifically about the acceptability of the online questionnaire: (1) I feel comfortable with completing the online questionnaire via the SMS link; (2) It was troublesome to complete the online questionnaire on a weekly basis. Each item was rated on five-point Likert scale of “strongly disagree” to “strongly agree.”

### *Data Analysis*

Survival of patients was assessed to ascertain if all patients survived beyond the 16-week period of the study when the weekly online questionnaires were sent. For completion of weekly symptom monitoring questionnaires, frequency and percentage of patients who completed more than 70% (12 out of 16) of the weekly IPOS questionnaires were computed. A completion rate of 70% was chosen as this was the trial feasibility

criteria used in a similar study of the stepped care model.<sup>15</sup> Multivariable logistic regression was used to assess factors associated with more versus less than 70% completion of weekly questionnaires.

In order to describe a snapshot of the types of palliative care concerns reported by patients with advanced cancer, responses to the online questionnaire in week one were used to assess the prevalence of symptoms and concerns identified by IPOS. Frequency and percentages of IPOS responses were tabulated.

Results from the feedback survey administered at the end of 16 weeks were tabulated to show frequency and percentage of response to the two items relating to the administration of weekly online questionnaires.

### *Sample Size Considerations*

In the larger randomized controlled trial, 120 patients were recruited in the intervention group. If the true completion rate of IPOS questionnaires was 70%, a sample size of 120 would give a precision level (width of 95% confidence interval) of  $\pm 8\%$  in the estimation of IPOS completion rate.

## **Results**

### *Participant Characteristics*

Demographic and clinical characteristics of the 120 enrolled patients who received weekly symptom monitoring are shown in [Table 1](#). The mean age was 61.2 years, 57.5% were male, 40.0% had postsecondary level of education and 32.5% were employed in a full-time job. Most of the patients had either gastrointestinal (35.0%), lung (23.3%), prostate (11.7) or head and neck (10.8%) type of primary cancer. Almost all patients had a good Eastern Cooperative Oncology Group (ECOG) performance status of either zero (37.5%) or one (55.0%).

### *Prevalence of Palliative Care Concerns at Baseline*

A total of 80 patients completed the IPOS questionnaire in week one ([Table 2](#)). Less than 20% had at least moderate distress from a symptom in the physical domain, except for weakness or lack of energy (18, 22.5%) and sore or dry mouth (25, 31.3%). A total of 33 (41.3%) patients reported feeling anxious or worried about their illness or treatment at least sometimes; 44 (55.0%) reported that their family or friends had been anxious or worried about them at least sometimes. In the communication and practical issues domain, 37 (46.3%) patients reported having as much information as they wanted only sometimes or less.

### *Screening Completion Rate and Associated Factors*

Out of the 120 patients, 111 patients survived beyond 16 weeks. The number of participants who

Table 1  
Baseline Characteristics (N = 120)

	Frequency (%)
<b>Male gender</b>	69 (57.5)
<b>Race</b>	
Chinese	99 (82.5)
Malay	13 (10.8)
Indian	2 (1.67)
Others	6 (5.0)
Age, mean (SD)	61.2 (11.8)
<b>Marital status</b>	
Married	85 (70.8)
Single	18 (15.0)
Divorced/ separated	9 (7.5)
Widowed	8 (6.7)
<b>Education level</b>	
No formal education	7 (5.8)
Primary school	16 (13.3)
Secondary school or ITE	49 (40.8)
Postsecondary (diploma, degree etc)	48 (40.0)
<b>Employment status</b>	
Full-time	39 (32.5)
Part-time	5 (4.2)
Retired	46 (38.3)
Housewife	13 (10.8)
Unemployed	17 (14.2)
<b>Functional status (ECOG)</b>	
0	45 (37.5)
1	66 (55.0)
2	6 (5.0)
3	3 (2.5)
<b>Cancer type</b>	
Gastrointestinal	42 (35.0)
Lung	28 (23.3)
Prostate	14 (11.7)
Head and neck	13 (10.8)
Genitourinary	11 (9.2)
Others	12 (10.0)
<b>Anticancer therapy at baseline</b>	
Surgery	51 (42.5)
Radiotherapy	56 (46.7)
Chemotherapy	98 (81.7)
Immunotherapy	28 (23.3)

completed the IPOS questionnaire at each time point is shown in [Supplementary Tables 1 and 2](#). For the 111 patients who survived beyond 16 weeks, the mean number of questionnaires completed was 9.2 out of 16 (58%). A total of 53 out of the 111 patients (48%) completed more than 70% (12 or more out of 16) of the questionnaires. In multivariable regression modelling, higher education level was found to be associated with higher completion of the weekly symptom monitoring questionnaires ([Table 3](#)). Compared to those with primary school education or less, those with secondary school level of education had 10.92-fold and those with postsecondary level of education had 49.19-fold increase in odds of completing more than 70% of the weekly questionnaires.

#### Acceptability of Weekly Online Questionnaire Completion

Patients were invited to complete a feedback survey at the end of the 16-week period. A total of 79 out of

111 patients responded (71% response rate). For the item “I feel comfortable with completing the online questionnaire via the SMS link,” 67 (85%) responded agree or strongly agree and nine (11%) were neutral. For the item “It was troublesome to complete the online questionnaire on a weekly basis,” 11 (14%) responded agree or strongly agree and 25 (32%) were neutral ([Table 4](#)).

#### Discussion

In this study to assess the feasibility of administering weekly patient-reported outcome measures in the context of a stepped care model, our main findings were: i) 58% mean completion rate and ii) 48% of the patients completed more than 70% of the weekly questionnaires for 16 weeks. Higher education level was associated with higher completion of patient-reported outcomes. From the feedback survey, 85% felt comfortable with completing the online questionnaires via the SMS link and 14% felt it was troublesome to complete it on a weekly basis.

Our completion rate of 58% is much lower than the 89% median patient-reported outcomes completion rate observed in oncology trials submitted to the US Food and Drug Administration.<sup>3</sup> This higher completion rate of 89% reported elsewhere may be due to patients being in earlier stages of cancer and the context of highly motivated patients participating in clinical trials. Furthermore, these patient-reported outcomes were completed as trial outcomes rather than screening questionnaires to identify symptoms and concerns for further clinical management within a stepped care model of palliative care service delivery. Also, the frequency of PROM administration in other studies may be less than weekly; the less frequent administration may be less disruptive, thereby facilitating a higher completion rate. However, only 14% reported feeling it was troublesome to complete the questionnaire on a weekly basis – this suggests that there are factors other than frequency of administration contributing to the low completion rate.

Zimmermann et. al. reported a Phase II trial conducted among patients with advanced cancer where patient-reported outcomes were administered in the clinic waiting rooms before every outpatient clinic visit to screen for clinical concerns that should be addressed during the visit. Using feasibility criteria of 70% completion rate, they found that 77% of the patients completed patient-reported outcomes for at least 70% of the visits.<sup>15</sup> This was much higher than the 58% observed in our study, where patient-reported outcomes were administered remotely on a weekly basis regardless of whether or not the patient had outpatient clinic visits scheduled. This suggests that patient-reported outcomes may be more feasible with higher

Table 2

**Prevalence of Symptoms and Concerns as Measured By Integrated Palliative Care Outcome Scale (IPOS) in Week One (N = 80)**

Frequency (%)	Not at all	Slightly	Moderately	Severely	Overwhelmingly	Moderately, severely, or overwhelmingly
Pain	35 (43.8)	33 (41.2)	9 (11.3)	3 (3.8)	0	12 (15.0)
Shortness of breath <sup>a</sup>	35 (44.3)	36 (45.6)	8 (10.1)	0	0	8 (10.0)
Weakness or lack of energy <sup>a</sup>	20 (25.3)	41 (51.9)	12 (15.2)	4 (5.1)	2 (2.5)	18 (22.5)
Nausea (feeling like you are going to be sick)	45 (56.3)	25 (31.3)	8 (10.0)	2 (2.5)	0	10 (12.5)
Vomiting (being sick)	66 (82.5)	10 (12.5)	2 (2.5)	2 (2.5)	0	4 (5.0)
Poor appetite <sup>a</sup>	37 (46.8)	27 (34.2)	9 (11.4)	5 (6.3)	1 (1.3)	15 (18.8)
Constipation <sup>a</sup>	45 (57.0)	25 (31.7)	9 (11.4)	0	0	9 (11.3)
Sore or dry mouth	29 (36.3)	36 (45.0)	10 (12.5)	10 (12.5)	5 (6.3)	25 (31.3)
Drowsiness	44 (55.0)	25 (31.3)	8 (10.0)	2 (2.5)	1 (1.3)	11 (13.8)
Poor mobility	45 (56.3)	27 (33.8)	3 (3.8)	4 (5.0)	1 (1.3)	8 (10.0)
	Not at all	Occasionally	Sometimes	Most of the time	Always	Sometimes, most of the time, or always
Q3. Have you been feeling anxious or worried about your illness or treatment?	21 (26.3)	26 (32.5)	25 (31.3)	6 (7.5)	2 (2.5)	33 (41.3)
Q4. Have any of your family or friends been anxious or worried about you? <sup>a</sup>	10 (12.7)	25 (31.7)	23 (29.1)	14 (17.7)	7 (8.9)	44 (55.0)
Q5. Have you been feeling depressed?	36 (45.0)	23 (28.8)	19 (23.8)	2 (2.5)	0	21 (26.3)
	Always	Most of the time	Sometimes	Occasionally	Not at all	Sometimes, occasionally, or not at all
Q6. Have you felt at peace?	20 (25.0)	27 (33.8)	21 (26.3)	8 (10.0)	4 (5.0)	33 (41.3)
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	23 (28.8)	20 (25.0)	22 (27.5)	9 (11.3)	6 (7.5)	37 (46.3)
Q8. Have you had as much information as you wanted? <sup>a</sup>	16 (20.3)	35 (44.3)	19 (24.1)	6 (7.6)	3 (3.8)	28 (35.0)
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	28 (35.0)	15 (18.8)	25 (31.3)	9 (11.3)	3 (3.8)	37 (46.3)

<sup>a</sup>This item had one missing response.

completion rates when administered in conjunction with a clinic visit rather than as a standalone process. Furthermore, the clinic waiting room may be a more conducive environment for PROMs completion compared to remote location where the patient may be engaged in other activities not related to their cancer condition.

We found that those lower levels of education had lower completion rates of patient-reported outcomes. Given their higher vulnerability and risk of poor health outcomes, these patients may ironically be the very group that would benefit from more support enabled by the routine PROM results. Additional support to complete patient-reported outcomes could be rendered to those with lower education – these may include individualised assistance or tailored user guides. Perhaps noncompletion of patient-reported outcomes could itself be a trigger to initiate a triage assessment to ascertain if there are symptoms or concerns that may benefit from an extra layer of support for the patient.

As part of baseline data collection, we described a snapshot of the range of palliative care symptoms and concerns that patients with advanced cancer may face – wide-ranging symptoms in the physical, emotional and communication domains. As many as 41% reported feeling anxious or worried about their illness or treatment at least sometimes, and 55% reported that their family or friends were anxious or worried about them. Having a cancer diagnosis is life-changing stressful event, made more complicated now with the rapidly increasing range of treatment options. In the context of having an advanced cancer that is incurable, deciding between treatments that often come with significant burden can be fraught with complexity. At the same time, patients have to navigate the challenges of how this advanced cancer diagnosis impacts their family and social world. These symptoms and concerns may be under addressed by the health-care team, supporting efforts to implement patient-reported monitoring of palliative care issues in order to facilitate early identification and prompt

**Table 3**  
**Demographic and Clinical Characteristics of Those Who Completed More vs. Less Than 70% of Questionnaires (N = 111)**

Characteristic	Completed less than 70% (11 or less out of 16) (n = 58) Frequency (%)	Completed more than 70% (12 or more out of 16) (n = 53) Frequency (%)	P value	Adjusted odds ratio <sup>a</sup>	P value
Male gender	32 (55.2)	31 (58.5)	0.72	0.80	0.72
Race			0.17		
Chinese	47 (81.0)	45 (84.9)		Ref	-
Malay	9 (15.5)	3 (5.7)		0.39	0.27
Indian	0	2 (3.8)		-	0.99
Others	2 (3.5)	3 (5.7)		2.0	0.57
Age, mean (SD)	62.2 (11.9)	59.8 (11.7)	0.29	1.0	0.56
Marital status			0.91		
Married	41 (70.7)	38 (71.7)		Ref	-
Single	9 (15.5)	9 (17.0)		1.26	0.75
Divorced/ separated	4 (6.9)	4 (7.6)		2.13	0.44
Widowed	4 (6.9)	2 (3.8)		0.67	0.76
Education level			< 0.01		
No formal education	4 (6.9)	2 (3.8)		7.83	0.22
Primary school	14 (24.1)	1 (1.9)		Ref	-
Secondary school or ITE	24 (41.4)	19 (35.9)		10.92	0.04
Postsecondary (diploma, degree etc)	16 (27.6)	31 (58.5)		49.19	<0.01
Employment status			0.71		
Full-time	16 (27.6)	21 (39.6)		Ref	-
Part-time	3 (5.2)	2 (3.8)		0.30	0.34
Retired	24 (41.4)	17 (32.1)		0.57	0.40
Housewife	7 (12.1)	6 (11.3)		1.64	0.64
Unemployed	8 (13.8)	7 (13.2)		0.60	0.55
Functional status (ECOG)			0.25		
0	18 (31.0)	24 (45.3)		Ref	-
1	35 (60.3)	26 (49.1)		0.41	0.09
2	4 (6.9)	1 (1.9)		0.14	0.20
3	1 (1.7)	2 (3.8)		0.23	0.39
Cancer type			0.16		
Gastrointestinal	24 (41.4)	14 (26.4)		1.31	0.77
Lung	9 (15.5)	18 (34.0)		0.54	0.61
Prostate	5 (8.6)	8 (15.1)		2.38	0.40
Head and neck	6 (10.3)	5 (9.4)		3.69	0.20
Genitourinary	6 (10.3)	4 (7.6)		0.54	0.45
Others	8 (13.8)	4 (7.6)		Ref	-
Anticancer therapy at baseline					
Surgery	26 (44.8)	22 (41.5)	0.72	1.03	0.96
Radiotherapy	25 (43.1)	26 (49.1)	0.53	1.79	0.29
Chemotherapy	48 (82.8)	41 (77.4)	0.48	0.53	0.38
Immunotherapy	11 (19.0)	14 (26.4)	0.35	1.41	0.58

<sup>a</sup>Multivariable logistic regression.

**Table 4**  
**Responses to Feedback Survey (N = 79)**

Frequency (%)	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
I feel comfortable with completing the online questionnaire via the SMS link	1 (1)	2 (3)	9 (11)	32 (41)	35 (44)
It was troublesome to complete the online questionnaire on a weekly basis	20 (25)	23 (29)	25 (32)	10 (13)	1 (1)

management of these highly prevalent but often overlooked psychosocial issues.

Even though the IPOS was designed to be used in routine clinical practice for longitudinal outcomes monitoring by palliative care teams, we chose to use the IPOS questionnaire as a screening tool because of its clinical relevance to this trial of stepped palliative care for patients with advanced cancer. Further research could be done to explore if the original intent

for the use of IPOS in routine palliative care clinical practice could be expanded to include the use of IPOS to screen for palliative care symptoms and concerns among patients with advanced serious illnesses but who are not yet referred to palliative care services.

#### Limitations

This study has several limitations. First, those who were unable to complete patient-reported outcome

measures were excluded from the study, which may affect generalisability of the results. Further analysis could be done to determine if inability to complete the online questionnaires is in itself associated with poorer outcomes and should trigger a triage assessment by the nurse. Second, in the feedback survey, there may be conflation of information for the item “I feel comfortable with completing the online questionnaire via the SMS link.” The findings reported here represent the participant’s comfort level with both the questionnaire and the online platform.

### Conclusion

In conclusion, within the context of a stepped care model utilising patient-reported outcome measures to proactively monitor for symptoms and concerns, completion rates of patient-reported outcomes were suboptimal. In order to improve the patient-reported outcomes completion rate, the timing of administration could be adjusted to be aligned with scheduled healthcare visits; the importance of completing the patient-reported outcomes could also be communicated to the patient by the healthcare provider during these clinic visits. To increase the completion rate among those with a lower education level, alternative modes of administration or additional support could be offered to complete the PROM questionnaires. Also, the stepped care model could be modified such that noncompletion of patient-reported outcomes could trigger a triage assessment. There is a need for further research on how to improve the uptake of patient-reported outcomes in real-world clinical settings<sup>16–20</sup> In order to ensure that the patient’s perspective is prioritised in everyday clinical practice, the incorporation of patient-reported outcomes should be applied beyond the context of clinical trials to routine palliative care provision.<sup>21</sup>

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*Supplementary table 1*

**Number of Participants Who Completed IPOS at Each Time Point Among All Participants in the Intervention Group (N = 120)**

Timepoint	Completed IPOS, n (%)
Week 1	80 (67)
Week 2	79 (66)
Week 3	73 (61)
Week 4	75 (63)
Week 5	70 (58)
Week 6	58 (48)
Week 7	72 (60)
Week 8	61 (51)
Week 9	63 (53)
Week 10	58 (48)
Week 11	68 (57)
Week 12	59 (49)
Week 13	54 (45)
Week 14	57 (48)
Week 15	55 (46)
Week 16	58 (48)

*Supplementary table 2*

**Number of Participants Who Completed IPOS at Each Time Point Among Those Who Survived 16 Weeks or More (N = 111)**

Timepoint	Completed IPOS, n (%)
Week 1	74 (67)
Week 2	75 (68)
Week 3	69 (62)
Week 4	73 (66)
Week 5	67 (60)
Week 6	57 (51)
Week 7	70 (63)
Week 8	61 (55)
Week 9	63 (57)
Week 10	57 (51)
Week 11	68 (61)
Week 12	59 (53)
Week 13	54 (49)
Week 14	57 (51)
Week 15	55 (50)
Week 16	58 (52)